WLGA RESPONSE TO THE CONSULTATION ON THE UPDATED CHILDREN AND YOUNG PEOPLE’S CONTINUING CARE GUIDANCE

AUGUST 2019

About Us

1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

2. The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

3. The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

Introduction

4. As recognised by the consultation document the legislative landscape in Wales has changed significantly since the current guidance was published in 2012, with several important pieces of legislation being introduced that have direct relevance to continuing care. These include the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. Given this changing landscape and the legal duties and responsibilities contained in these new pieces of legislation it is appropriate that the existing guidance is updated to reflect these changes.

5. Feedback from practitioners has also highlighted that the existing guidance was too focussed on process, which came at the expense of actual outcomes. We therefore welcome the opportunity to provide comments on the updated guidance document and support the ambition to ‘put the child at the heart of the process’.

6. WLGA are aware that local authorities are planning their own submissions in response to the consultation, many of which will consider the practical and operational impact of the changes contained in the detail of the guidance. Our response instead focusses on some of the key issues that we believe need further consideration and clarification from Welsh Government in relation
to the future provision of children and young people’s continuing care, which fall under question 1 in the set consultation questions.

Q1. Is the guidance clear as to who Children and Young People’s Continuing Care is for and are the criteria for eligibility clear?

7. The eligibility criteria for Children and Young People’s Continuing Care (CYP CC) is not clearly laid out in the guidance, other than reference to the toolkits contained as annexes within the guidance and statements that suggest that “a continuing care package will be required when a child or young person has long-term needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone” and that “continuing care...is additional to care which is provided either as a universal service, or a specialised service.” It would be helpful to be clearer on the eligibility and it may be helpful to learn from the adults NHS continuing care (CHC) guidance which clearly sets out that eligibility for CHC is when an individual’s primary need has been assessed as health-based. Given the aspiration to make the child or young person and their parents and carers the focus of the continuing care process, using person centred practice and a “what matters” approach is essential and so the revised guidance needs to ensure that it reflects a needs led approach rather than being service led.

8. Section 2.1 of the guidance sets out the differences between CYP CC and NHS continuing care (CHC). The guidance recognises that in the case of CHC, which covers people aged 18 years or over assessed as having a health-based primary need, then this is a complete package of ongoing care arranged and funded solely by the NHS through Local Health Boards (LHBs). Here the NHS is responsible for providing for all of the individual’s assessed health and associated social care needs, including accommodation, if that is part of the overall need.

9. The guidance recognises that the term continuing care is “used to highlight the similarities to NHS Continuing Healthcare” and that the main reason for such a package “will derive from the child or young person’s health needs”. However, it goes on to identify that, “If a child or young person is found to be eligible for children and young people’s continuing care (CYP CC,) the LHB is not the responsible body for funding any social care which may be needed - this remains a LA responsibility.” Further clarification is needed as to why the approach taken for adults in receipt of continuing health care is different to that of children and young people in receipt of continuing care and it would be helpful for this clarity to be provided before moving ahead with implementing any new guidance.

10. The draft CHC guidance currently out for consultation highlights the importance of Section 47 of the Social Services and Well-being (Wales) Act (The SSWB Act) in identifying the extent of local authorities’ powers in relation to the provision of health services. Section 47 makes it clear that that a local authority may not meet a person’s needs for care and support by providing or
arranging for a service which is required to be provided under a health enactment, unless doing so would be incidental or ancillary to doing something else to meet those needs. Part of the intent of The SSWB Act was to move towards supporting ‘people’ rather than separating out adults and children and so Section 47 is equally applicable to both. The result is that under CHC once a person’s health care needs are outside the limits of social care funding responsibility shifts to the NHS.

11. Deciding on the balance between local authority and health service responsibilities with respect to long-term care has been the subject of key court judgments. The Judge in the Haringey Judgement, highlighted in the draft guidance, applied the Coughlan criteria, used to determine whether a local authority or a Primary Care Trust (PCT) should provide required services to an adult in need of continuing care, equally to children as for adults. Given that Section 47 of The SSWB Act is equally as applicable to children as it is for adults, then as is the case under CHC it can be interpreted that there is no justification to distinguish between adult continuing healthcare and children’s continuing care, with the effect being that as with CHC, once a child or young person becomes eligible for continuing care the NHS becomes responsible for providing for all of the individual’s assessed health and associated social care needs.

12. We would welcome further discussions with and further clarity from Welsh Government on this issue to be able to understand the current position as set out in the guidance, with a need to further examine the existing case law, the impact of the Haringey Judgement and the need to align eligibility criteria’s for both adult and children’s continuing care. This approach may also help with the transition process as a young person moves from CYP CC into CHC.

Other comments

13. Annex B includes a check list for consideration of CYP CC eligibility, whilst appreciating that the guidance does identify that the checklist is not a substitute for the continuing care process and that the outcome does not necessarily indicate eligibility for continuing care there are some concerns about how it might lead to some decisions being made. The guidance on the checklist refers to the need to be used in conjunction with a nursing assessment and implies that it is to be completed by a health assessor. It is also essential that any social care assessments are used and that social workers are also engaged in the process. The check list itself breaks down the care domains into three levels of severity: A – representing the highest level of needs; B – representing some level of need; and C – representing low level of need. The checklist states that:

“A score of mainly C’s would indicate that care needs are low and /or routine and could be met through core services. A score of mainly B’s may indicate the need for continuing care depending on level of input required and skills. May require full assessment for
consideration for children and young people’s continuing care. Mainly A’s would indicate nursing needs and consideration for children and young people’s continuing care.”

14. This may be an overly simplistic way of considering needs and could potentially set thresholds at too high a bar. It would be worth considering the CHC approach where scoring highly in one, two, or three domains indicates eligibility, rather than needing to do so across all domains. It would also be helpful to provide advice as to what actions should be taken if the outcome is that the child or young person is unlikely to be eligible for a continuing care assessment.

15. In addition, there does not appear to be any advice or guidance to support the Decision Support Tool (DST) that is included in Annex B that would assist with making a decision on eligibility. The adult guidance for example provides more advice and guidance, which should help support a broad approach to summarising the needs under nature, intensity, complexity and unpredictability, where having sufficient needs under any one of the four headings would indicate eligibility. The adult DST also broadly uses domains scoring with, for example one ‘Priority’ or two ‘Severe’s’ could indicate eligibility. Although it is emphasised that scoring is only an indicator it can help and aid in consistency in decision making and the QA process.